Scientific Workshop on Lesbian Health 2000

Steps for Implementing the IOM Report

Department of Health and Human Services
Office on Women's Health

National Institutes of Health
Office of Research on Women's Health

Gay and Lesbian Medical Association (GLMA) and the Lesbian Health Fund (LHF)

Organizing Sponsors

- Department of Health and Human Services, Office on Women' s Health
- National Institutes of Health, Office of Research on Women' s Health
- Gay and Lesbian Medical Association (GLMA) and the Lesbian Health Fund (LHF)

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- Lyon-Martin Women' s Health Services
- National Gay and Lesbian Task Force
- Sexual Minority Youth Assistance League (SMYAL)
- The Mary-Helen Mautner Project for Lesbians with Canter
- Women' s Program Office and Lesbian, Gay, Bisexual Concerns Office of the American Psychological Association

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EXECUTIVE SUMMARY

During the last decade, scientific interest in lesbian health has risen, in parallel to the national focus on women's health in general. The impetus for this attention came about in the early 1990s when the national media focused on the potentially higher risk for breast cancer in the lesbian population. In addition, the National Lesbian Health Advocacy meetings with Federal agencies in 1993 led to the initiation of many activities within the Department of Health and Human Services. The inclusion of questions on sexual behavior and identity in the Federally funded Women's Health Initiative and the Nurses Health Study was a major step for lesbian health during this decade. The supplemental funding provided by the NIH Office of Research on Women's Health to study the lesbian population was instrumental in stimulating research projects.

Among nongovernmental organizations, the funding of small research grants by the Lesbian Health Fund of the Gay and Lesbian Medical Association, totaling about $250,000 this decade, established valuable pilot data for larger research projects. Several medical organizations passed resolutions for the inclusion of or protection of persons by sexual orientation. Scientific articles on lesbian health have also appeared in several peer-reviewed medical and public health journals in recent years.

In 1999, the Institute of Medicine published its landmark report, *Lesbian Health: Current Assessment and Directions for the Future*. NIH's ORWH and CDC's Office of Women's Health led the effort to support this first-of-a-kind study. The recommendations were broad and overarching. The IOM report was well received according to IOM representatives, with more than 5,000 copies distributed to health care professionals and government officials nationwide. Given the challenge in implementing the recommendations, the Gay and

Lesbian Medical Association invited the DHHS Office on Women' s Health and ORWH to co-sponsor a workshop to identify the next steps needed to implement the IOM recommendations. Several other government agencies joined in sponsoring this workshop, as well as several lesbian, gay, bisexual, and transgender organizations and health professional organizations. We want to especially thank these groups for their support and participation in this important workshop.

On March 23-24, 2000, over 100 lesbian health experts, and government and foundation representatives met at the Scientific Workshop on Lesbian Health in Washington, D.C. (Appendix 1). Representatives from the National Center for Health Statistics and the Substance Abuse and Mental Health Services Administration provided valuable and new information on the inclusion of questions on sexual identity and behavior in the National Health and Nutrition Examination Survey and the National Household Survey on Drug Abuse, respectively. Lesbian health experts enlightened the workshop participants on the history of the lesbian health movement, as well as the CDC-funded "Removing the Barriers Project" that provides culturally appropriate training for health care providers. A video, *Lesbian Physicians: Practice, Patients, and Power* revealed the barriers lesbians face in receiving quality health care. Representatives from the gay community who prepared the White Paper for Healthy People 2010 presented the science base to justify the inclusion of sexual orientation in the tracking of dozens of Healthy People objectives.

Participants spent most of the workshop in one of ten working groups on the following topics: Cancer, Cardiovascular Disease and Obesity, Health Promotion and Intervention, HIV/AIDS and STDs, Life Span Development, Mental Health and Substance Abuse, Research Career Development, Research Methodology, Resiliency/Health Effects of

Homophobia, and Service Delivery and Access to Services. Each working group was asked to consider several research questions that were raised by the IOM report, which are included in each section of this report, as well as the eight general recommendations from the IOM Report (see page viii). Each working group was charged with producing at least five implementation steps. Specific activities suggested by each working group provide a rich menu of programs for Federal and private organizations to choose from for future support. They range from activities that require minimal financial support to activities that require more substantial long-term funding.

A summary of the most frequently recommended steps for implementation from the Working Groups is shown in Appendix 2. Two recommendations were endorsed by all ten working groups: 1) The Federal government should solicit and fund research on lesbian, gay, bisexual, and transgendered health; and 2) Research should include the diversity of the lesbian population in terms such as race/ethnicity, socioeconomic status, age, disability, and geography. The justification for these recommendations was apparent after a search for currently funded grants or contracts on lesbian health in DHHS revealed very few funded projects. Lesbian health researchers were encouraged to submit sound scientific proposals to Federal health agencies to be considered for funding. Eight of the working groups suggested the continuance of scientific workshops or professional meetings on lesbian health, and asked that such conferences be supported at regular intervals. Seven of the working groups suggested steps be taken to improve access to the health care system, such as funding studies to explore the causes for barriers that lesbians have in accessing health care, treatment, information, and preventive services. Along the same lines, seven working groups recommended that cultural competency/sensitivity training be provided for health

care providers and researchers. The CDC-funded "Removing the Barriers Project" was suggested as a model in this regard.

Seven working groups also called for the inclusion of sexual orientation for analysis in federally funded research. The National Health Interview Survey, the Youth Risk Behavior Survey, the National Health and Nutrition Examination Survey, plus several ongoing disease-specific surveys were mentioned for inclusion of questions on sexual orientation and/or for oversampling the lesbian, gay, bisexual, and transgendered population. The invited experts were surprised to learn that several federally funded health surveys have or currently collect information on sexual orientation. Over half (six) of the working groups called for the funding of research to determine the appropriate methodology for studies conducted on the lesbian population.

The creation of liaison positions in relevant DHHS agencies collected information clearinghouses for lesbian, gay, bisexual, and transgender research was recommended by working groups (six). In July, 2000 DHHS created the Steering Committee on Disparities Related to Sexual Orientation, which includes representatives from most of the DHHS agencies and offices. This committee has been asked to develop a strategic plan for the DHHS by the end of the year. Special studies on the impact of discrimination, stigma, and homophobia on mental and physical health was also called for by half of the working groups. In all, 70 steps for implementing the IOM report were suggested by the expert working groups. These recommendations will be considered in developing the strategic plan for the department.

Another positive event that has occurred since the Scientific Workshop on lesbian health is the announcement that Healthy People 2010 will include sexual orientation as a population group for

tracking in almost 30 objectives. A Healthy People Companion document had also been commissioned to highlight lesbian, gay, bisexual, and transgendered health as related to the national objectives.

The process of implementing the IOM report on lesbian health has now begun. Researchers and others inside and outside government are invited to use the proceedings of this workshop to ensure that lesbian health needs are more fully addressed in research proposals. Likewise, members of the lesbian community are encouraged to participate in these unique research opportunities. Integrating these workshop recommendations into continuing or new health research efforts should yield significant progress by the end of the decade in addressing issues raised by the IOM report.

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IOM RECOMMENDATIONS CONSIDERED BY EACH WORKING GROUP

- Increase knowledge of health risks and protective factors, improve data-gathering methodologies for gathering information about lesbian health, increase understanding of the diversity of the lesbian population, and improve access to health care services.

- Improve measurement of the various dimensions of lesbian sexual orientation.

- Include questions about sexual orientation on data collection forms in relevant studies in the behavioral and biomedical sciences.

- Consider the full range of racial, ethnic, and socioeconomic diversity among lesbians in study design; include study population members in development and conduct of research; and protect the confidentiality and privacy of the study population.

- Fund a large-scale probability survey to determine the range of expression of sexual orientation among women and the prevalence of various risk and protective factors for health by sexual orientation.

- Convene regular conferences to disseminate information re: the conduct and results of lesbian health research, including the protection of human subjects.

- Develop and support mechanisms for Federal agencies„ foundations, health professional associations, and academia to disseminate information on lesbian health to health care providers, researchers, and the public.

- Develop strategies to train pre- and post-doctoral researchers in conducting lesbian health research.

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PREPARATION OF THE REPORT

The Scientific Workshop on Lesbian Health was a success largely due to the countless hours given by the 10 Working Group Chairs and the Planning Committee, comprised of members of the Lesbian Health Fund, the Gay and Lesbian Medical Association, and Federal representatives.

Likewise, the hard work of the more than 100 experts and leaders in lesbian health from LBGT organizations, health care organizations, academia, foundations, and HHS agencies is reflected in this report. Judith Grant and Lynn Peniston of the MayaTech Corporation should be thanked for their excellent logistical support at the conference. Finally, Matthews Media Group should be acknowledged for their timely preparation and editing of the recommendations.

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1. Cancer Working Group

IOM Report: Key Points

"Much attention has been paid to possible increased risk of cancer among lesbians, particularly with respect to breast cancer. The assumption of higher risk for lesbians is based primarily on data from various studies suggesting that certain cancer risk factors occur at higher levels or with greater frequency in lesbians. These factors include higher rates of smoking, alcohol use, poor diet, greater BMI, and differential rates of hormone exposure associated with less use of oral contraceptives and the lower likelihood of bearing children. To date, however, there are no epidemiological studies supporting a conclusion that lesbians are at increased risk for breast or other cancers.

"There are several reasons for studying cancer among lesbians. For example, compared to heterosexual women, lesbians may have differences in risk factors, differences in prevalence of risk factors for each of the cancers, and differences in the way that health care is received (e.g., how they relate to their health care provider, how the provider relates to them)."

IOM Suggested Areas for Research

- Population-based studies to determine the incidence of cancer among lesbians

- Prevalence of cancer risk factors among lesbians (e.g., hormone replacement therapy use, diet, overweight, alcohol use, and tobacco use)

- Patterns of screening behaviors among lesbians (e.g., mammograms, Pap smears)

- Possibilities for adding sexual orientation items to cancer and SEER registries

- Need for prevention and treatment intervention models targeted specifically toward lesbians.

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Cancer Working Group Recommendations

1. Federally funded data systems should include sexual orientation measures. Specifically:

   - NHIS should use both sexual orientation questions and sexual behavior questions for stratifying survey results.

   - NHANES should oversample lesbians, as is currently done for African Americans and Hispanics.

   - CDC's BRFSS should ask questions about sexual orientation and behavior as they relate to cancer risk factors and utilization of screening.

   - CDC's YRBS should add sexual orientation/behavior as an analytical category.

2. Other ways of including sexual orientation in federally funded studies should be explored. Specifically:

   - CDC's National Breast and Cervical Cancer Early Detection Program should fund a feasibility study to assess collection of data regarding sexual orientation and behavior.

- Measures should be taken to determine the feasibility (e.g., by oversampling or by other methodology) of collecting data on sexual minorities from the CDC cancer registry and the NCI SEER registry.

3. Federal agencies should adopt policies that are inclusive of sexual minorities. Specifically:

   - ORWH should develop a package describing measures of sexual orientation/behavior. This material should be distributed to all NCI and other cancer investigators performing research on human subjects.

   - All SEER special studies should be required to measure and report data stratified by sexual orientation/behavior.

   - Sexual minority status should be incorporated in the list of "special populations" or "medically underserved" persons as defined by the Office of Special Populations Research at NCI.

   - "NIH Guidelines for Inclusion of Women and Minorities as Subjects in Clinical Research" should be amended to include sexual minority status.

   - Federal funding in clinical settings should be made contingent on completion of cultural competence training. This training should be modeled on the CDC-funded Mautner project "Removing the Barriers" for all personnel in contact with patients.

4. Relevant agencies should issue a call for "better than the best" statistical methodology in studies utilizing Federal funding mechanisms (e.g., RFPs, RO1 grants) addressing multiple social, biological, behavioral, and cancer risk factors stratified by

orientation/ behavior, degree of public disclosure, age of parity, and gender role/appearance/identity. Data should also track:

- Nullparity
- Obesity
- Smoking
- Alcohol consumption
- Screening compliance
- Stress
- Social support
- Diet
- Environment
- Occupational exposure
- High-risk sex with men
- Number of partners
- Exercise
- Medications
- Family history/genetics
- DES exposure
- Oral contraceptive use history
- Events related to stigmatization, such as violence, verbal harassment, discrimination

5. Relevant agencies should issue a call for "better than the best" statistical methodology in federally funded studies to evaluate predictors of screening utilization rates for mammograms, Pap smears, fecal occult blood tests, sigmoidoscopy, and clinical breast exams. These studies should be stratified by sexual orientation/behavior with special emphasis on:

   - Stressors regarding screening
   - Financial access to screening
   - Fear of provider
   - Anticipatory fear of homophobia
   - Distrust of medical institutions
   - Providers' information/cultural competence

- Gender role/appearance/identity
- Body self-concept emphasis

6. Funds should be made available for a special study that stratifies data in cancer registries by orientation/behavior based on measures of time from diagnosis to treatment, and on stage, type of treatment (including complementary), and other treatment variables for breast, colon, cervical, lung, and ovarian cancers.

7. Mechanisms should be created to improve training for educators, researchers, and students. Specifically:

   - In order to reduce barriers and improve access to health care for sexual minority patients, agencies should fund pilot studies on cultural competence training for students and health care providers.

   - This meeting (Scientific Workshop on Lesbian Health) should be convened every two years to assess progress.

   - Relevant agencies should devise methods to cement implementation of recommendations prior to administrative turnover.

8. Healthy People 2010 should include sexual orientation/ behavior. Specifically, Healthy People 2010 should contain:

   - Calculated death rates from cancers stratified by sexual minority status (cite "DNC" where data not counted).

   - Measures of sexual orientation and behavior in data collection efforts relevant to cancer prevention, including Pap smears, colorectal screening, and mammograms (objectives 3-11, 3-12, and 3-13).

- Specific reference to lesbian/bisexual women in the stated goals of Healthy People 2010. Examples include Objective 27-1, reduce tobacco use by adults; Objective 27-2, reduce tobacco use by adolescents; Objective 27-5, increase smoking cessation attempts by adult smokers; and Objective 27-7, increase smoking cessation attempts by adolescent smokers.

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2. Cardiovascular Disease and Obesity Working Group

IOM Report: Key Points

> "There are no population-based data on cardiovascular disease among lesbians or on the factors that increase their risk for cardiovascular disease. There is some evidence that lesbians may have higher rates of smoking and higher BMI, two risk factors for cardiovascular disease. On the other hand, lesbians are less likely to use oral contraceptives, which may lower their risk for cardiovascular disease. Based on currently available data, the committee concludes that it is not possible to determine whether lesbians are indeed at higher risk for cardiovascular disease than women in general."

IOM Suggested Areas for Research

- Population-based studies to determine incidence of cardiovascular diseases among lesbians
- Prevalence of risk factors for cardiovascular diseases among lesbians (including tobacco use, diet, overweight, hypertension, diabetes, and cholesterol), as well as prevalence of physical activity and hypertension and cholesterol screening
- Dietary patterns of lesbians and prevalence of overweight and eating disorders
- Use of oral contraceptives and hormone replacement therapy among lesbians

- Prevalence of cigarette smoking among lesbians and patterns of tobacco use

- Studies of interventions that work for lesbians

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Cardiovascular Disease and Obesity Working Group Recommendations

1. Sexual orientation should be added as an analytical category to federally funded research. Specifically:

    - Sexual orientation should be added to existing large-scale studies, including the Framingham Heart Study, SWAN, Black Women's Health Survey, and the National Health Interview Survey.

    - All new NIH applicants should be required to address sexual orientation as part of the "diversity rule."

    - A standard "significant other" question(s) should be distributed to federally funded primary investigators.

2. Relevant Federal agencies should take measures to advance education and awareness within the research infrastructure. Toward this end:

    - A program should be implemented wherein project officers and members of the Center for Scientific Review are

trained under a system used by the Director's Office for previous diversity rules.

- OPRR should create educational materials for IRBs.

- Institute-based workshops regarding scientific issues (e.g., new cardiovascular risk data) should held on a regular basis.

- The existing minority programs should provide supplemental training funds for lesbian/gay/bisexual awareness.

- Primary investigators should be trained in lesbian/gay/bisexual sample recruitment with particular emphasis on community collaboration.

3. A broad study of lesbian and bisexual women's health should be funded and should use a probability or a multi-center small area, cross-sectional research design (as opposed to the more costly longitudinal study). Specifically, the survey should evaluate:

    - Smoking
    - Body fat
    - Hip/waist ratio
    - Dual energy x-ray absorptiometry measures
    - Diet
    - Food frequency questions
    - Physical activity assessment
    - Glucose tolerance
    - Blood profile lipids
    - Other serum risk factors such as Homocysteine
    - Mental health indicators
    - Alcohol use
    - Use of complementary and alternative medicine

- Socioeconomic status
- Determinants of key risk factors

This study should solicit support from community groups.

4. Federal funding mechanisms should be created to conduct a two-stage risk factor intervention trial:

   - Stage 1 will assess and tailor standard interventions based on the following variables: a) attitudes toward focus groups and past intervention experience; and b) the knowledge base of women at risk for cardiovascular disease.

   - Stage 2 will develop community-based demonstration projects that take into account multiple risk factor interventions.

5. Relevant Federal agencies should develop a comprehensive lesbian community education initiative regarding cardiovascular risk factor awareness, screening recommendations, and related issues. This education program should:

   - Target smoking cessation.
   - Broaden the health agenda based on a possible substudy that explores how lesbians get health information, and who they hold credible as health advisors.

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3. Health Promotion and Intervention Working Group

IOM Report: Key Points

"As for lesbian health research in general, information is limited on the prevalence of particular health risk factors among lesbians. The Women's Health Initiative (WHI) provides one useful source of data for looking at differences between lesbian and heterosexual women in the study in terms of certain health-related risk variables.

"Data from the WHI indicate significant differences in cigarette smoking status depending on sexual orientation. Approximately twice as many lesbians were reported to be heavy smokers compared to heterosexual women (6.8% of lifetime lesbians and 7.4% of mature lesbians versus 3.5% of heterosexual women).

"Body mass index (BMI), an indication of overweight, differed significantly between lifetime lesbians and heterosexual women in the WHI, with a greater proportion of lifetime lesbians having a BMI of more than 27 (52.3% of lifetime lesbians compared to 45.8% of heterosexual women).

"In the WHI sample, lesbians were much less likely to have ever been pregnant than were heterosexual women. These differences were particularly pronounced for lifetime lesbians of whom 34.1% had previously been pregnant, compared to 61.2% of the mature lesbians and 89.9% of the heterosexual women.

"Not surprisingly, lifetime lesbians in the WHI sample were least likely to report having used oral contraceptives between the ages of 25 and 35 (only 16.7%). Approxi-

mately one-third of heterosexual women (32.0%) had used oral contraceptives during this age period as had 42.4% of mature lesbians.

"Alcohol use among lesbians is described in more detail in a later section of this report dealing with mental health and substance abuse.

"Finally, most studies of lesbians indicate that their experiences of childhood sexual abuse are about the same as those of heterosexual women."

IOM Suggested Areas for Research

- Efficacy of current smoking and breast cancer prevention projects
- Etiology of substance use and abuse
- Risk and protective factors across the life span
- Involvement of lesbians in lesbian-centered community organizations and activities and their impact on lesbian health
- How to encourage lesbians in healthy behaviors and how to bring them in for care
- Interventions specifically geared to prevent health risk behaviors and events among lesbian adolescents (e.g., STDs, cigarette smoking, substance abuse)

Health Promotion and Intervention Working Group Recommendations

1. Sexual orientation should be added to all RFAs and RFPs targeted for minority populations or women's health funding. Toward this end, agencies should:

    - Supplement this directive with diversity training toolkits for government program staff as necessary.

    - Establish an Office of Lesbian and Gay Health. This office will be responsible for 1) enforcing culturally-competent guidelines; 2) ensuring that reviewers are aware of the guidelines; and 3) designing appropriate research questions concerning sexual orientation.

2. Research should evaluate a model lesbian-focused smoking cessation program, comparing it to a conventional smoking cessation program.

3. A comparative analysis should be conducted of "ask the nurse" Internet chat rooms versus chat rooms designed specifically to address the health concerns of lesbian, gay, bisexual, and transgender youth. Comparisons should include coverage of the following topics: alcohol, drugs, teen pregnancy, smoking, HIV, STDs, and sexual assault.

4. Agencies should develop and evaluate lesbian health curricula modeled on the Kaiser Program for medical schools, nursing schools, and public health programs.

5. Health care provider sensitivity training modeled after the Mautner Project and Rankow/ Rimer programs should be provided.

6. Interventions should be furnished to practicing health care providers; they should be modeled after the California State Breast and Cervical Cancer Screening Program.

7. An evaluation should be performed of the effectiveness of community-based lesbian organizations compared to well established women's health or gay organizations (with a lesbian liaison). The study should compare the effectiveness of the respective programs in terms of recruiting lesbians, and especially lesbian women of color, for services such as alcohol treatment and Pap smear screening.

8. Healthy People 2010 should include lesbian/bisexual women. Specifically, the Healthy People objectives should address the following issues as they relate to lesbian and bisexual women:

    - High school graduation rates
    - Homelessness
    - Use of breast cancer screening
    - Internet access to health care sites
    - Level of physical exercise
    - Health care providers' attitudes
    - Alcohol consumption and abuse over the course of the life span

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4. HIV/AIDS and Sexually Transmitted Diseases Working Group

IOM Report: Key Points

"Although it is well known that women can acquire STDs from male sex partners, the risk of STD transmission between female partners is unclear. Guidelines for safe sex for lesbians are lacking. Attempts to use national or local surveillance data to estimate the risk of STD transmission between women are limited by the fact that many risk classifications schemes have either excluded same-gender sex among women or subsumed it under a hierarchy of other behaviors viewed as higher risk. Moreover, few if any state or local STD reporting systems routinely collect and analyze information on same-sex behavior among women. Nonetheless, lesbians are often perceived to be at very minimal risk for STD….

"The prevalence of HIV infection among women who have sex with women (WSW) is unknown owing to the methodological barriers in attaining representative samples of these women and the lack of HIV research studies targeting these populations. The few studies of WSW that assess HIV seroprevalence provide differing estimates of HIV infection rates, possibly attributable to the type of WSW populations sampled. Most studies, however, suggest higher HIV seroprevalence among WSW compared to exclusively heterosexual women….

"HIV-related research on WSW, regardless of sexual orientation, has been scarce yet notable for its unexpected findings:

- Higher HIV seroprevalence rates among women who have sex with both women and men (i.e., behaviorally

bisexual women) compared to their exclusively homosexual or heterosexual counterparts;

- High levels of risk for HIV infection through unprotected sex with men and through injection drug use; and

- Risk for HIV infection of unknown magnitude owing to unprotected sex with women and artificial insemination with unscreened semen."

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IOM Suggested Areas for Research

- Mechanisms operating to increase HIV risk among injection drug-using women who have sex with women

- Research on the risk networks of injection drug-using women who have sex with women

- High-risk sexual and injection behaviors among women who have sex with women

- Risks of STDs (including HIV) transmission through female-to-female sex

- Measurements of sexual partnerships and sexual networks (including HIV status of male sex partners)

- Prevalence of bacterial vaginosis among women who have sex with women

- Sexual histories of lesbians, including history of sexual contact with men

- Prevalence of infections related to injection drug use, such as hepatitis B and C

NOTE ABOUT TERMINOLOGY: In this chapter, the terminology mirrors that of the IOM Lesbian Health report in that we use "women who have sex with women" in the context of STDs. The purpose of this term is to include those women who don't self-identify as lesbian or bisexual but who are potentially at risk for female-to-female transmission of STDs.

HIV/AIDS and Sexually Transmitted Diseases Working Group Recommendations

1. To supplement multi-city IDU cohorts, HIV research should examine women who have sex with women and use injection drugs. To improve the quality of the research, these studies should:

   - Oversample women who inject drugs and have sex with women
   - Include supplemental questions
   - Provide assistance in interpreting results

2. Since the risk of female-to-female transmission of STDs is not well known, Federal funding should be made available for studies that quantify and characterize female-to-female sexual risk of:

   - HIV, by expanding sites in the existing CDC study
   - Hepatitis B and C
   - Herpes virus
   - Syphilis
   - Bacterial Vaginosis
   - Gonorrhea

- Human papilloma virus (HPV)
- Chlamydia
- Other STDs

3. Because the CDC HIV/AIDS surveillance hierarchy may underestimate female-to-female transmission and HIV infection in women who have sex with women, a review and evaluation of the CDC HIV/AIDS surveillance system should be conducted. Specifically, this evaluation should:

    - Followup on reports with missing risk data
    - Analyze data from states and cities that have added sexual orientation to their surveillance form

4. Since sexual identity and behavior questions are not included on many large behavioral surveys, Federal programs should direct funds to, and provide technical support for, adding sexual identity and behavior questions to:

    - YRBS
    - SAMHSA's National Household Survey of Drug Abuse
    - BRFSS
    - Other surveys

5. Appropriate agencies should fund targeted population studies that are inclusive of all age and socio-demographic groups. These studies should be designed to define when and how women who have sex with women are at risk for STDs and HIV.

6. Since HIV-positive women who have sex with women may encounter unique barriers to prevention and care services, Federal programs should:

    - Use data from existing studies to identify patterns of utilization and barriers to accessing prevention and care services.

- Include questions in new studies of HIV-positive women that address prevention and care issues for women who have sex with women.
- Fund studies and interventions to address barriers unique to women who have sex with women.
- Fund studies to determine effectiveness of barrier methods for preventing woman-to-woman transmission of HIV, and to examine porosity and compliance/ behavior in utilizing the barrier method.

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5. Life Span Development Working Group

IOM Report: Key Points

"Very little information is available about specific developmental issues that might emerge in childhood for lesbians. There is a larger although still limited research base on homosexuality in adolescents. Little of this work, however, has focused exclusively on lesbians. Further, systematic longitudinal studies of development and adjustments are lacking. Finally, earlier research, particularly that which focused on pathological behavior, may be of less relevance to understanding the well-being of contemporary lesbian adolescents given the contextual changes in society that have acted to increase the visibility of homosexuality and the availability of support systems for lesbian and gay youth.

"Many of the developmental issues that adult lesbians face are the same as those faced by other women: entering the workforce, finding a loving partner and developing a satisfying sexual life, deciding whether to have children, being a parent, negotiating the aging process with its attendant declines in health and, for some, the death of a life partner. Little information is available, however, about how lesbians face these challenges through adulthood or about the unique challenges they may face. For example, there is a dearth of research on the practice and meaning of sexuality for lesbians throughout their life course. There is evidence that most lesbians have been heterosexually active, and this complicates retrospective and prospective analyses.

"Deciding whether or not to have children is an important and sometimes difficult issue for all women whether lesbian or heterosexual. In addition to all the usual parenting

issues, lesbian parents must cope with the very real fear that they will lose their children in custody battles and other legal situations. Nonetheless, lesbians are increasingly choosing to become parents, often through donor insemination, but also through adoption and foster care."

IOM Suggested Areas for Research

- Process of coming out and what constitutes a psychologically healthy coming out
- Factors that help/hinder development of healthy self-esteem in lesbian adolescents
- Development of lesbian sexual identity
- Specific physical and mental health concerns of lesbians as they age, from childhood to old age
- Childbearing patterns of lesbians
- Development of sexual orientation
- Lesbian motherhood, including studies of children born into or adopted by lesbian-parented families

—Reprinted with permission from Institute of Medicine, *Lesbian Health: Current Assessment and Directions for the Future* (Institute of Medicine, 1999, pp. 50, 52-53, 85-86).

Life Span Development Working Group Recommendations

1. Definitions of lesbian sexual orientation should reflect the lesbian experience in terms of identity, attraction, behavior, and affiliation.

    - NCHS, through its Cognitive Lab, should develop valid and reliable measures of sexual orientation across the life span.

    - ORWH should issue an RFA, in collaboration with other institutes (e.g., NICHD and NIMH), to fund in-depth qualitative studies of sexual orientation development in diverse groups of lesbians (for example, in terms of race, ethnicity, class, and geographic area) across the life span. These studies should explore variations over time and across the life span, taking into consideration cultural and ethnic diversity, as well as proven techniques developed in other clinical and research areas.

2. Federal funding should be provided for studies (an RFA for longitudinal studies and a PA for qualitative studies) to examine the physical and mental health and life course effects of gender atypicality in childhood and adolescence across the life span (e.g., violence and suicide).

3. NICHD and NIMH should develop PAs for longitudinal studies of lesbian child-rearing, including decision-making, insemination, conception, birth, pre-school, and adulthood.

4. NICHD and NIMH should fund qualitative studies of lesbian family definition and structure, with sensitivity to multicultural issues.

5. Funding should be provided for longitudinal studies of lesbians over the age of 50, focusing on issues of mental health, physical health, insurance, workplace, retirement, access to care,

housing (including nursing homes), discrimination, and social support systems.

- NIMH and NIA should fund qualitative studies to explore and define the concept of successful aging in lesbians.
- Questions on sexual orientation should be added to existing longitudinal studies of aging (e.g., the Baltimore study).
- The National Institute of Nursing Research should provide funding for research on lesbian caregiving.
- AHRQ should fund a study on access to health insurance, health care, and health outcomes for lesbians.
- Sexual orientation should be included on the National Medical Expenditure Survey.
- Support should be given for a conference on health and mental health research related to lesbian aging.
- Information on sexual orientation should be included in disease registries and on death certificates.

6. Federal funding should be provided (RFAs, PAs by NIMH) to conduct in-depth studies on identity development and management across the life course. Researchers should focus on all aspects of identity development and management, including multiple stigmatized identities (e.g., in terms of sexual orientation, race, ethnicity, disability, and socioeconomic status).

7. DHHS should fund a clearinghouse to provide technical assistance on lesbian health research design, including access to archive datasets and shared information on lesbian health research. Furthermore, DHHS should:

- Provide training on lesbian health issues to the CSR study sections.

- Conduct seminars for grant applicants through CSR in order to encourage submissions and provide guidance on preparing research proposals on lesbian health issues. These efforts should be in conjunction with large professional meetings (e.g., APHA and APA) in different regions of the country.

8. Funding should be provided for an RFA or PA to: 1) examine the physical and mental health impact of anti-gay violence and family-related violence across the life span (e.g., schools to nursing homes) through NIMH, NIDA, and NIAAA; and 2) evaluate the amount of resources for victims of gay family-related violence. Specifically:

    - NCVS and NSFV should include a question on sexual orientation.

    - NIA and NICHD should fund studies (RFA or PA) on discrimination and anti-gay violence toward older lesbians and adolescents.

    - NIMH should fund a workshop for researchers on the role of stigmatization and anti-gay violence on health and mental health.

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6. Mental Health and Substance Abuse Working Group

IOM Report: Key Points

"Very little is known about the prevalence and incidence of depression, anxiety disorders, psychotic disorders, dissociative disorders, and personality disorders in lesbians. In general, studies have not found differences in the psychological adjustment of nonclinical samples of lesbians and other women. Although there is, in general, no reason to expect that most major mental illnesses occur more or less often in lesbians than in heterosexual women, except perhaps owing to the experience of discrimination, not enough information is available to draw definitive conclusions.

"Data on the use of alcohol among lesbians are not available from population-based samples or large-scale epidemiological studies focusing on alcohol use, although this area has received some research attention. Nonetheless, reviews of lesbian health research consistently include alcohol abuse as a problem for which lesbians appear to be at greater risk than heterosexual women, and alcohol abuse has been widely viewed as a prevalent and serious problem among lesbians.

"Data across a wide range of non-probability small-sample studies suggest that about 30% of lesbians may have alcohol problems. However, this estimate may be inflated since these studies have generally had a number of methodological problems, including the fact that subjects have often been recruited using convenience sampling from settings in which alcohol consumption is likely to occur (e.g., bars). Further, it has been suggested that contemporary patterns of alcohol use among lesbians may be lower because bars have become a less important component of the lesbian cul-

ture as other options for social gathering have become increasingly available."

IOM Suggested Areas for Research

- Prevalence of mental disorders among lesbians, including major depression
- Relationships between lesbians and their family members and their influences on mental health
- Impact of multiple minority statuses on the formation of lesbian identity and on mental health
- Normative mental health for lesbians across the life span
- Relationship between suicide and sexual orientation, particularly during adolescence
- Utilization of mental health services
- Impact of violence and other hate crimes on the lives of lesbians
- Effectiveness of various therapeutic approaches with lesbians
- Associations between childhood sexual abuse and substance abuse, including alcohol abuse
- Etiology of substance use and abuse (including alcohol) among lesbians

- Prevalence of heavy drug use and injection drug use among lesbians

—Reprinted with permission from Institute of Medicine: *Lesbian Health: Current Assessment and Directions for the Future* (Institute of Medicine, 1999, pp. 69, 79-80, 88-87).

Mental Health and Substance Abuse Working Group Recommendations

1. Federal agencies funding research and administering health programs should make a sustained effort to clearly communicate that concerns relevant to lesbian health are within the mainstream of science and public health efforts and thus within the primary mission of these agencies. In order to facilitate the acceptance of lesbian health research into the mainstream, Federal agencies should:

   - Issue RFAs and PAs on lesbian MH/SA research.
   - Include reference to lesbian MH/SA research in other relevant RFAs/PAs and in the descriptions of standing funding programs.
   - Include coverage of lesbian MH/SA research in all relevant NIH workshops and conferences.
   - Sponsor conferences and publications on cross-cutting issues, bringing together a variety of scientific and policy perspectives.
   - Designate particular program officials within each relevant agency component as responsible for promoting lesbian MH/SA research.

2. Given that the emerging science in lesbian MH/SA has documented higher than expected rates of functional and dysfunctional substance use and possibly greater prevalence of some mental disorders, an integrated approach to comorbidity issues in this population should be taken. Furthermore, in recognition of the scientifically known concurrence of MH/SA disorders and physical illness, this approach should include the development of integrated models for lesbian health research and service delivery.

3. Given that scientific evidence consistently documents both differential patterns of mental and physical health care utilization and the problems faced by lesbians in accessing culturally competent care, funding should be provided for research specifically focused on outcome issues in this population. In this regard, both prevention and treatment approaches to ameliorate the negative effects of bias and multiple stigmas are needed, including research on issues related to efficacy and effectiveness of interventions at multiple levels, including the individual, workplace, school, and community settings.

4. Support should be provided for research on those positive factors in individuals and communities that will enhance our understanding of how to improve lesbians' health and mental health status. To that end, support is needed for multiple research strategies that include both qualitative and quantitative methodologies at the individual and community levels.

5. In recognition of the diversity of the lesbian population on multiple dimensions (including identity, age, ethnic/ racial background, and social class), and to enhance the representatives and cultural competence of lesbian mental health and substance abuse research, guidelines should be developed for initiating and maintaining mutually beneficial collaborations between researchers and communities (both individuals and organizations).

6. Given the currently small pool of skilled researchers in the area of lesbian MH/SA, NIH and other relevant Federal agencies should solicit grant proposals for training and early career development, particularly in the areas of:

    - Multi-institutional research and training consortia (on the model of the successful NIMH family research consortia)

    - Conferences and short-term training programs on targeted research areas with high potential for progress

    - Mentored and independent career development awards

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7. Research Career Development Working Group

IOM Report: Key Points

"For numerous reasons, researchers in academic and other settings (e.g., independent research institutes, clinical research centers, community research organizations) have been reluctant to initiate research on lesbian health. Many of the historical barriers continue to affect what research is done, how it is perceived, what kinds of resources are made available, and the personal and professional impact on those who conduct lesbian research.

"The committee identified several factors that have acted to inhibit the conduct of research on lesbians. As has already been noted, some of the reluctance to conduct research in this area arises because of the difficult methodological challenges that researchers face in designing and implementing sound studies of lesbians (e.g., because lesbians have been a hidden population, finding a diverse and representative sample can be extremely difficult). There are numerous other barriers, including the potential negative effects on academic careers of working with a stigmatized population, the lack of mentors for conducing research in this area, and the lack of funding."

IOM Suggested Areas for Research

- Need for training
- Faculty support at the assistant, associate, and professor levels
- How to increase the number of lesbian PIs and co-PIs on grants

- Working with heterosexual researchers and PIs
- How to get lesbian women through the "double glass ceiling"
- How to obtain funding to design and fund programs for lesbian health research
- Develop ways to support lesbian health researchers in obtaining and utilizing already established lesbian health funding
- Career patterns and workplace experiences

—Reprinted with permission from Institute of Medicine: *Lesbian Health: Current Assessment and Directions for the Future* (Institute of Medicine, 1999, pp. 85, 135-144).

Research Career Development Working Group Recommendations

1. A Lesbian Health Research Consortium should be developed. Specifically:
    - The RFA for the consortium should include clinical, community, and research organizations. The consortia should: a) develop a mechanism to increase available study populations, give studies more statistical significance and scientific "validity," and provide for community grounding; b) create measures to increase participation of lesbians in clinical trials; and c) develop policy.
    - An annual lesbian health research conference should supplement the national lesbian health research consortium.

2. Measures should be adopted to improve institutional accountability. Specifically:

   - OWH should issue an annual report on lesbian health.
   - A specific staff person at OWH should be dedicated to lesbian health.
   - DHHS should implement a systemwide inclusion of lesbian health research in Healthy People 2010 (see Objective 23-4).
   - Lesbian health and research should be included in the programs of professional health organizations and academic accrediting organizations (e.g., Liaison Committee on Medical Education, National Library of Medicine, American Association of Critical Care Nurses, and Council on Education for Public Schools).
   - ORWH should conduct and evaluate training for scientific review administrators and Institute Center (IC) staff to raise awareness of the IOM report findings.

3. An RFA for a lesbian health research Web site should be issued. The site should enhance the research environment, and should include:

   - Bibliographies
   - List of researchers and mentors in lesbian health
   - List of qualified reviewers
   - Technical assistance in grant writing
   - Information on funding sources
   - List of existing/available databases
   - Descriptions of research-in-progress
   - List of training opportunities

4. Measures should be taken to promote an agency-wide increase and improvement in information-gathering resources. Specifically, this agency-wide effort should:

    - Use existing databases that include information on sexual orientation/behavior (e.g., NHANES, NHIS).
    - Expand all federally funded large population-based surveys to include dimensions of sexual orientation.
    - Collaborate with other investigators to encourage the inclusion of questions about sexual orientation.
    - Provide supplemental funding for special studies (e.g., SEER).
    - Fund a longitudinal lesbian health cohort study.
    - Conduct a 20 year observational study modeled on the Framingham Heart Study to evaluate the prevalence/ incidence of health risks and health outcomes.
    - Develop a valid definition of "lesbian."
    - Ensure that participants are ethnically, racially, and economically diverse.

5. Improvements should be made in the recruitment and retention of faculty. Specifically, there should be mechanisms to:

    - Train deans and department heads in lesbian cultural competency.
    - Encourage visiting professorships.
    - Establish lesbian health research fellowships.

- Add lesbian health research as a priority area in women's health training grants (e.g., Building Interdisciplinary Research Careers in Women's Health).

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8. Research Methodology Working Group

IOM Report: Key Points

"Conducting research on lesbian health presents numerous challenges because lesbians represent a subgroup of women for which standard definitions of the population are lacking and lesbians are not readily identifiable. These challenges are further compounded because many in the lesbian community distrust research and researchers and there has been little funding support for conducting research on lesbian health topics. It is not surprising then, that methodologically rigorous large-scale studies are lacking in this area. Furthermore, a number of methodological challenges for comparing findings across studies are consistently found in lesbian health research.

"Studies have not been consistent in how they define a lesbian sexual orientation, with some focusing on sexual behavior and others focusing on identity or desire. Also, "studies of lesbian health have lacked standard measures of sexual orientation including its three components—behavior, identity, and attraction or desire—which makes comparisons among studies difficult. Most lesbian health studies have relied on non-probability samples. However, few studies have allowed direct comparisons between lesbians and other subgroups of women by using the same sampling strategies to identify subjects across sexual orientations and including measures of sexual orientation. Most existing studies portray cross sections of experience at one point in time, rather than development over time."

IOM Suggested Areas for Research

- Need or lack of need for definitions of lesbian, lesbian behavior, and woman-woman sexual/affective behavior

- Need for and usefulness of measures for definition and examination of lesbians in varying contexts and research environments

- Cognitive research needed to determine proper questions for use with lesbians i.e. highly closeted lesbians who are difficult to reach for study, including cognitive laboratory testing, audio-CASI, and other techniques

- Confidentiality issues

- Study design issues

- Measurement of sexual partnerships and sexual network

—Reprinted with permission from Institute of Medicine, *Lesbian Health: Current Assessment and Directions for the Future* (Institute of Medicine, 1999, pp. 97-130).

Research Methodology Working Group Recommendations

1. Where scientifically appropriate, sexual orientation should be measured in all federally funded studies, and lesbians should be included in all federally funded studies of women. All DHHS agencies and institutes will receive these recommendations and develop a plan to be implemented beginning FY 2002. DHHS includes NIH, HRSA, SAMHSA, and CDC (including NCHS).

2. Methods for measuring sexual orientation should be improved. Toward this end, researchers and relevant Federal agencies should:

   - Conduct cognitive tests to identify and develop "best practice" methods (for question wording and modality) for collecting data on sexual orientation/identity, attraction/desire, partner gender, and reference periods. Priority survey techniques should include in-home paper self-administered questionnaires with an interviewer, audio-CASI, telephone CASI, and individual mail surveys. Other techniques should include household mail surveys; CATI (random-digit dial, listed); CAPI or paper interview; and Web-based surveys.

   - Evaluate the advantages and disadvantages of each method and technique based on age, education, geography, socioeconomic status, race and ethnicity, and "outness" as part of the cognitive testing.

   - Conduct a randomized trial of these survey techniques to compare their validity and reliability, including response/participation rates.

3. Federal funding should be provided for a wide range of qualitative and quantitative studies that include a number of designs shown in Table 1 and Table 2 (pp. 8-7 and 8-8). Survey designs should address:

   - How to design the best cohort. For example, survey designs should explore ways to identify sufficient numbers of lesbians and sufficient numbers of subgroups of particular interest (e.g., based on race/ethnicity, age, and nonurban location).

   - The inclusion of sexual orientation in Federal surveys, including survey-specific implementation and language recommendations

- Measures to strengthen statistical analysis in 3-generation studies
- Analysis of existing datasets (including cross-sectional surveys)
- Inclusion of hard-to-reach populations in each study design

4. Special methodological studies should be conducted to assess appropriate research designs for studies of lesbian and bisexual women. Specifically, relevant Federal agencies should:

   - Convene a workshop to explore changes in methods and study designs that will enhance lesbian health research.
   - Conduct a feasibility study of the inclusion of appropriate sexual orientation measures (after testing through cognitive studies) in Federally funded health surveys. Include attention to operations issues, such as reducing the fragmentation of Federal efforts, and maximizing interagency resources and capacity.
   - Fund secondary analysis of existing datasets, including cross-sectional surveys with probability and nonprobability samples.
   - Fund exploratory research on sampling low-prevalence populations with specific attention to methods for identifying groups such as rural lesbians and highly closeted lesbians.
   - Fund an exploratory study to identify ways to recruit a cohort that secures sufficient numbers of lesbians and subgroups of interest (e.g., race/ ethnicity, age, and nonurban residence).
   - Fund a subsequent cohort study on lesbian health, including a heterosexual comparison group.

- Fund research that explores new statistical analysis methods for 3-generation studies.

5. In view of the sensitive nature of the population, all research should give special consideration to the issues of confidentiality and privacy. Specifically:

   - The standard procedures for confidentiality and privacy may not provide the protection needed for lesbians, both because lesbians are a small population and because they have a history of discrimination.

   - OPRR needs to examine and review current procedures and recommendations in order to ensure that research on lesbians is appropriately protected and enhanced. Results should be broadly disseminated by NIH scientific workshops and changes should be implemented by FY 2002.

   Practices that should be considered to ensure confidentiality include handling of data, informed consent, data storage, follow-up procedures, and data collection methods.

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TABLE 1: QUANTITATIVE RESEARCH METHODS

Study Design	Suitable Areas/Topics	Methodological Issues	Value-Added
Cohort studies	Risks/incidence of heart disease, breast cancer, lung cancer, depression, obesity, diabetes in lesbians as compared to heterosexual women within the same cohort Also life change/ development issues	Selection method Sample size Comparisons: sisters, friends, or heterosexuals recruited using the same sampling strategy as lesbians New cohort can be built or existing cohort can be studied, pros for both.	Most valuable method for discussing differential effects of and resistance to disease between lesbians and heterosexuals
Longitudinal	To study change in effects in health status over time in relation to health behaviors; can examine life events within the lesbian community (e.g., coming out, going in, marriage, divorce, break up with partner, death of partner) **Pro**: Smaller sample than cohort study; can be only lesbians **Con**: Loss to followup challenge	If heterosexuals, ensure that they are comparable to lesbians	Good for studying life-change issues
Case control	Same as prospective cohort **Pro**: Cheap and fast **Con**: Recall bias; bad for 'rare exposure' (such as lesbianism)	Some problems solved by a variant design which requires nonstandard statistical analysis	Consensus: As defined by the epidemiologic community, it is not appropriate for these research questions
3-Generation	Useful in looking at family and developmental issues. **Pro**: Very useful for ethnic minority communities **Con**: statistics problems	Researchers are struggling with analysis challenges	Might be very useful in the future, after the methodology is strengthened

Study Design	Suitable Areas/Topics	Methodological Issues	Value-Added
Randomized prevention/Intervention	Studying the effectiveness of culturally appropriate interventions in studying risk factors **Pro**: Efficacy can be definitively established **Con**: Intervention may be less effective in practice	Loss to followup, ensuring and measuring compliance, developing potentially successful lesbian-specific interventions	The only way to develop and test interventions
Cross-sectional	2 major types: probability and nonprobability *Nonprobability designs* **Pro**: Good for measurement of sexual partnerships and networks, good for exploratory issues. Community studies, cultural issues. **Con**: Limited generalizability *Probability designs* **Pro**: generalizable **Con**: expensive	*Nonprobability* Building a sophisticated sampling strategy **Probability** ***Challenges in getting disclosure/question design***	**Nonprobability** Can build a large number of participants, inexpensive

TABLE 2: QUALITATIVE RESEARCH METHODS

Study Design	Suitable Areas/Topics
Ethnographic	Coming out process, human sexuality issues
Focus Groups	Pretesting, variable development, language development, propensity to respond
Case Analysis or Case Series	Explore rare or underreported events (e.g., hate crimes)

9. Resiliency/Health Effects of Homophobia Working Group

IOM Report: Key Points

"There is little information about the social norms of lesbians communities and how these norms might have an impact on health risk. Likewise, little information is available about the risk or protective effects of lesbian relationships. One factor hypothesized to play an important role in lesbian health is stress.

"Lesbians, similar to other stigmatized individuals, likely experience stress related to the difficulties of living in a homophobic society. Stress may result from the burden of keeping one's lesbian identity secret from family or coworkers, being excluded by physicians from making health care decisions for a gravely ill lesbian partner or, among many other factors, being the target of violence or other hate crimes. Hostility and isolation are very potent forms of stress that contribute to allostatic load by leading to elevated levels of the stress hormones. Although the precise health effects of stress on lesbians have not yet been examined systematically, some hypotheses can be made about their possible health risk based on information about both the stress effects of discrimination on other groups and the stress effects of socioeconomic status. It can be hypothesized that lesbians who experience such forms of psychosocial stress sustain negative effects similar to those of other groups that experience discrimination.

"It can also be hypothesized that stress effects may be greatest for lesbians who are subject to multiple forms of discriminations, for example, lesbians who are also members of racial or ethnic minority groups. In addition to experiencing racism encountered by members of racial and

ethnic minority groups in general, minority lesbians can also encounter racism in the lesbian community. Racism may thus compound the negative effects that homophobia potentially has on health. The combination of homophobia, racism, and sex-based discrimination has been referred to as being in triple jeopardy.

"A variety of factors can act to protect individuals from negative outcomes, including a close relationship with a responsive and accepting parent, attachment to external support systems such as schools or churches, and having well-developed social support systems. Although research is quite limited, some factors have been suggested to be protective of lesbian health. One of the suggested protective factors is involvement in the lesbian community. Although midlife lesbians responding to the NLHCS reported high levels of stress, most reported that they relied on the lesbian community and on lesbian and gay male friends for support and socialization and reported overall satisfaction with their lives."

IOM Suggested Areas for Research

- Impact of homophobia, prejudice, and discrimination on physical/mental health relative to expressed, inherent, or internalized homophobia
- Protective factors across the life span—coping and resiliency factors
- Reduction of homophobia in research and researchers in this area
- Stress effects of various aspects of homophobia and their influence on health

- Lesbian social support networks

- Sources of stress for lesbians and the impact of stress on their physical and mental health

—Reprinted with permission from Institute of Medicine, *Lesbian Health: Current Assessment and Directions for the Future* (Institute of Medicine, 1999, pp. 59-61, 63,85-86,135-140).

Resiliency/Health Effects of Homophobia Working Group Recommendations

1. A broad conceptual framework should be developed. This framework will inform and instruct all research.

2. A life-span framework should be developed. Specifically, relevant Federal agencies should:

   - Develop a cultural framework that includes ethnicity, race, and socioeconomic status.

   - Establish flexible ways to identify lesbians (e.g., identity, behavior, orientation, and desire).

3. Funding should be granted to increase knowledge of health risk and protective factors. Specifically, funding should support:

   - Studies of the effects of homophobia, heterosexism, sexual prejudice, and related issues on lesbian physical and mental health.

   - Studies of the effect of disclosure (coming out or not) on the physical and mental health of lesbians, particularly disclosure to health care providers. Studies could include, but

are not limited to, those modeled on Landrine and Klonoff's study of how sexism affects women's health.

- Studies of physiological markers of stress.

- Research on the causes of homophobia.

- Research on the impact of discriminatory public policy and legislation on lesbians' physical and mental health (e.g., impact of military policy on lesbian service members and impact of the Defense of Marriage Act).

- Studies of the effect of the direct and indirect violence on lesbian, bisexual, and transgender individuals' physical and mental health.

4. Measures should be taken to decrease homophobia on the part of research and researchers in order to improve data gathering methodologies.

5. Measures should be taken to overcome barriers to obtaining accurate data and representative sampling. Specifically, relevant Federal agencies should:

   - Require that material on sexual orientation issues be included in training programs.

   - Create linkages between researchers and people in the communities that are being studied.

6. There should be a concerted effort to improve access to health care services, and to understand the effects of various aspects of homophobia and their influence on physical and mental health. Toward that end, relevant Federal agencies should:

   - Conduct research on management of sexual identity throughout the life span.

- Conduct research to determine the relationship between societal and/or internalized homophobia and how women who have sex with women identify their sexual orientation and behavior.

- Determine the health consequences associated with how women label their sexual orientation and behavior.

- Conduct research on the utilization of family and social support networks.

- Determine the health consequences of being out or closeted. Specifically, we recommend a research agenda that: a) determines the effects of coming out or not at different developmental stages; b) provides a situational analysis of when coming out is protective; and c) assesses the benefit/harm of "don't ask, don't tell" as a personal coping strategy.

- Develop and support mechanisms for government, foundations, health professional associations, and academia to disseminate information on lesbian health to health care providers, researchers, and the public.

- Organize research conferences on critical issues such as: a) the health effects of homophobia on older lesbians, and b) the health effects of violence on adolescent lesbians, bisexuals, transgender individuals, and youth questioning their sexuality.

7. Researchers should take measures to increase the knowledge of health risks and protective factors. Specifically, researchers should:

    - Conduct studies on the structure and function of family life among lesbians, including research on family of origin,

families of choice, family formation, and development of family over time. Research topics might include: a) the relationship between families' responses to sexual orientation and future psychological resilience or vulnerability; and b) research on the construction of kinship relations, including those with past partners.

- Conduct comparative studies in lesbian relationships and heterosexual relationships.

- Determine the relationship of family—broadly defined (for example the multitude of family structures that are created in the lesbian community)—in terms of coping and resiliency versus risk throughout the life span. Examine how the family serves as a protective factor and as a source of stress across the life span.

8. Sexual orientation issues should be a required part of the curricula in all federally funded training programs for physical and mental health care providers.

9. Policies/mechanisms should be adopted to increase knowledge of health risks and protective factors, particularly in regard to the impact on physical/ mental health of homophobia, prejudice, and discrimination relative to expressed inherent or internalized homophobia. Toward this end, we suggest training for teachers, school counselors and school personnel in junior high schools and high schools in sexual orientation issues and the special vulnerabilities of adolescent lesbian, bisexual, and transgender individuals.

10. Strategies should be developed to train providers to improve access to health care services. Specifically, researchers should:

    - Conduct assessment of existing interventions (e.g., curriculum development and sensitivity training) to evaluate their effectiveness.

- Conduct high quality evaluation research on methods designed to decrease homophobia. Methods might include video, sensitivity training, curricula, and intervention studies.

11. In order to understand the effects of health provider homophobia and its influence on lesbian health, researchers should conduct more studies on attitudes toward lesbian clients and consumers among a broad range of physical and mental health providers.

Participants

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10. Service Delivery and Access to Services Working Group

IOM Report: Key Points

"Lesbian health and risks to health can be examined in the context of the health care system. In other words, there are aspects of the health care system that act to reduce lesbian's access to services, thereby possibly increasing their risk of health problems.

"Structural barriers that affect health care for lesbians included *potential* barriers presented by managed care systems and the fact that lesbians relationships are often not afforded the same legal standing as heterosexual marriages.

"Although domestic partner benefits are now increasingly available through some employers, most lesbians still do not have the option of coverage under their partner's health insurance plan.

"Hospitals and health care providers do not always give the partner of a lesbian patient, or the co-parent of a lesbian's child, the same rights to visit and to access information as is provided to a heterosexual spouse.

"Since insurance coverage is the primary gateway to health care in this country, lesbians are at a distinct disadvantage relative to married heterosexual women because of the common prohibition against spousal benefits for unmarried partners. "Personal and cultural barriers that affect access to care for lesbians include the lack of cultural competency among health care providers, the fear of *coming out* to providers, and the lack of lesbian focus in preventive and other health care."

IOM Suggested Areas for Research

- Lesbians' patterns of use of health care services
- Models of care that act to remove barriers of access to care for lesbians
- Impact of managed care on quality of care for lesbians
- What constitutes a basic standard of care for lesbian health
- Whether cultural competency training of providers on the needs of lesbians will increase sensitive delivery of health care for lesbians
- Access to health insurance for lesbians
- Need for prevention and treatment intervention models targeted specifically toward lesbians
- Barriers to care for lesbians, including adolescent lesbians
- Extent to which treatment facilities for alcohol and drug problems provide adequate care for lesbian clients

—Reprinted with permission from Institute of Medicine, *Lesbian Health: Current Assessment and Directions for the Future* (Institute of Medicine, 1999, pp. 37, 40-42, 86-87).

Service Delivery and Access to Services Working Group Recommendations

1. In order to improve cultural competence, the Federal government—in partnership with professional organizations and other agencies already concerned with cultural competency in health care—should fund the expansion and evaluation of the efficacy of the Mautner Project "Removing the Barriers" and similar programs. Specifically:

    - Within these partnerships, steps should be taken to develop, test, and implement components and models for fostering culturally competent systems of care through mechanisms such as demonstration projects, RFPs, and funding priorities.

    - Health care accrediting bodies such as the Joint Commission on Accreditation of Healthcare Organizations and the National Committee on Quality Assurance should require that delivery systems demonstrate cultural competence in sexual orientation, gender, ethnicity, race, class, age, national origin and disability in training of personnel, policies, accessibility, and hiring.

    - Professional licensure bodies should require the demonstration of cultural competence as a criterion for entry. A minimum of 10% of items on entrance exams will test cultural competence.

2. Measures should be taken to remove the barriers imposed by heterosexual bias. Whereas there should be ongoing efforts to educate and sensitize as many providers and health care institutions as is possible through traditional, continuing education and innovative methods, access to safe and competent care, based on appropriate research, is of immediate concern. Efforts to define "lesbian" and to measure risks and problems in

health care delivery will require methodological inquiry and long-term studies.

- A potentially more direct means of establishing what lesbians should have as a basic standard of relevant and culturally competent care might begin with the elimination of heterosexual bias in research, provider education, and health programming.

- To this end, all Federal level funding mechanisms for research, training, and health service projects should be screened for heterosexual bias. This means that in addition to the usual review for efficacy, significance, and quality, grant proposals will have to meet additional criteria. It would be incumbent upon the grant author to establish these criteria and articulate them in the grant in much the same way that criteria have been used to increase the salience and inclusion of women and children in research.

- The absence of heterosexual bias would be demonstrated by the absence of the following assumptions (these are not exclusive). It will not be assumed that a) persons are always in coupled relationships; b) women have access to male partners' income and resources; c) families are all "traditional" or nuclear family structured; d) gender is a dichotomous feature; and e) reproductive health concerns are primary. Forms and surveys will not demonstrate these biases.

3. It is projected that as heterosexual bias decreases, researchers and providers will necessarily be faced with the need to innovate in order to accommodate the diversity of the many subpopulations of women, including lesbian, bisexual, and transgender women.

4. Further exploration of the access to health care and health insurance for lesbian, bisexual, and transgender women should

be taken by pursuing a national research project that addresses lesbian access to health care, and is representative of marginalized lesbians, including lesbians of color, lesbians with disabilities, lesbians in prison, lesbians in alcohol or drug treatment, and working class lesbians. The focus of the research should include:

- Prevalence of health insurance
- Source of health insurance (e.g., through employment, as a dependent, governmental program, privately purchased)
- Income
- Incidence of failure to receive health care because of lack of health insurance or money
- Other household members (children, partners) who lack health insurance (due to situations such as main wage earner lacking insurance or lack of a domestic partnership)

5. Support should be given to legislative actions that move in the direction of universal access to health care wherein health care is a right rather than a privilege for lesbians and for all individuals.

    - To meet the goal, partnerships with other groups working toward universal access will be necessary.
    - Until the goal of universal access is achieved, we must reduce inequities in the existing system of employment-based health coverage by lobbying for recognition of lesbian and gay couples and families in the design of employment benefit packages, and exploring the idea of equivalent benefit substitutions for single individuals who opt against dependent insurance coverage.

6. Funding should be made available for consumer education and outreach programs. Specifically, funds should be allotted for:

    - Research into how lesbian, bisexual, and transgender women seek health-related information and what health information they need
    - The creation of a dedicated support mechanism and funding for the collection and centralization of lesbian health information
    - The integration of lesbian-, bisexual-, and transgender-specific health information into general women's health Web sites and information systems

7. Funds should be allocated for contracts with informatics experts, marketing researchers, and other professionals to develop a multi-purpose and complex lesbian health Web site. Possible funding for the development of the Internet site could be part of an educational grant through governmental or private mechanism. It is acknowledged that many women do not have complete Web access, but this project should provide access for many women who in some regard meet criteria for being "lesbian" (desire, behavior, or identity) and who are isolated because they are rural, incarcerated, or young. The Web site should fulfill the following purposes:

    - Function in conjunction with NIH; CDC; SAMHSA; lesbian, bisexual, and transgender health associations, and private research foundations as a clearinghouse for establishing an emergent information resource relevant to lesbian health issues (including demographic data, risks, protective factors, and specific disease entities).
    - Provide a peer-refereed on line journal for practice— and research-related articles about women who are lesbian, bisexual, or transgender.

- Develop an accessible consumer clearinghouse and on-line forum that includes interaction with lesbian health experts who can address questions, concerns of the lesbian, bisexual, and transgender public.

- Data collections methodology to survey hidden populations.

8. Research-supported strategies should be developed for disseminating health information to older, rural, incarcerated, youth, and other underserved populations such as lesbians with disabilities, lesbians of color, and lesbians with low literacy or immigrant status.

9. Clear research priorities should be established. These priorities should build on the notion that access to services depends on an understanding of both provider and consumer experiences and perceptions. Specifically, research should:

    - Identify points of entry to care for lesbian, bisexual, and transgender women that may include diverse sites not previously included in studies (e.g., prisons, jails, detox centers, outpatient clinics, community mental health centers, nursing homes, and juvenile facilities).

    - Identify existing disparities in care and the assumptions on which they are based. These studies might follow the model of the cardiac studies on gender, racial disparities in treatment. For example, straight and gay persons might be compared to assess the inclusiveness, appropriateness, and quality of service provided based on sexual orientation differences. Specifically, the issue of frequency of Pap smears and utilization of mental health could serve as benchmarks for best care. It is acknowledged that further research is needed to identify the salient health risks and appropriate care for lesbians.

- Identify and document components and dynamics of provider-consumer interactions that produce positive and negative health outcomes based on lesbian identification.

- Establish and support regional centers of excellence for lesbian, bisexual, and transgender women's health. Full partners in these centers will include lesbian, bisexual, and transgender woman consumers, local community organizations, local health agencies, and policymakers.

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Appendix 1: Scientific Workshop on Lesbian Health Program/Agenda

The Washington Monarch Hotel
Washington, D.C.

March 23-24, 2000

THURSDAY, MARCH 23, 2000

	Wanda K. Jones, Dr.P.H.— Moderator Office on Women's Health
	INTRODUCTORY REMARKS
9:00 a.m. - 9:15 a.m.	**Vivian Pinn, M.D.** Office of Research on Women's Health
9:15 a.m. - 9:30 a.m.	**Maureen S. O' Leary, M.I.M.** Gay and Lesbian Medical Association
9:30 a.m. - 9:50 a.m.	**REVIEW OF IOM REPORT** **Introduction By: Vivian Pinn, M.D.** **Charles Evans, M.D., Ph.D.** Institute of Medicine (IOM)
9:50 a.m. - 10:00 a.m.	**Questions and Answers**

KEYNOTE SPEAKERS

10:00 a.m. - 10:15 a.m. **Raynard S. Kington, M.D., Ph.D.**
National Center for Health Statistics
The Experience of NCHS/CDC with Sexual Orientation Survey Questions

10:15 a.m. - 10:30 a.m. **Ulonda B. Shamwell, M.S.W.**
Substance Abuse and Mental Health Services Administration
The 1996 National Household Survey on Drug Abuse Experience with Sexual Orientation Items and Future Plans

10:30 a.m. - 10:45 a.m. **Randall L. Sell, Sc.D./Judy Bradford, Ph.D.**
Health Resources and Services Administration
Implications of the HP2010 White Paper Funded by HRSA

10:45 a.m. - 11:00 a.m. **BREAK**

Yvonne Green, R.N., M.S.N., C.N.M.¾ Moderator
Associate Director for Women' s Health
Centers for Disease Control and Prevention

THURSDAY, MARCH 23, 2000 (cont.)

11:00 a.m. - 11:15 a.m.	**Kate O' Hanlan, M.D.** The Lesbian Health Movement: How Far Have We Come and Where Do We Need to Go?
11:15 a.m. - 11:45 a.m.	**Dee Mosbacher, M.D., Ph.D.** Video Presentation *Lesbian Physicians: Practice, Patients, and Power*
11:45 a.m. - 12:00 Noon	**Sabrina Sojourner** Sojourner and Associates Director of Training for The Mautner Project *"Removing the Barriers Project/Mautner Project" Funded by the Centers for Disease Control and Prevention*
12:00 Noon - 12:15 p.m.	**Discussion of Keynote Speeches**
12:15 p.m. - 1:15 p.m.	**LUNCH**
1:15 p.m. - 1:30 p.m.	**INSTRUCTIONS FOR WORKING GROUPS** Suzanne Haynes, Ph.D. (OWH)
1:30 p.m. - 5:30 p.m.	**WORK GROUP SESSIONS** Cancer *Kate O'Hanlan, M.D., Chair*

Cardiovascular Diseases and Obesity
Susan Johnson, M.D., M.S., Chair

Health Promotion and Intervention
Suzanne Haynes, Ph.D., Chair

HIV/AIDS and STDs
Susan Chu, Ph.D., M.S.P.H., Chair

Life Span Development
Caitlin Ryan, M.S.W., A.C.S.W, Chair

Mental Health and Substance Abuse
Susan Cochran, Ph.D., M.S., Chair

Research Career Development
Alice Dan, Ph.D., Chair

Research Methodology
Judy Bradford, Ph.D., Chair

Resiliency/Health Effects of Homophobia
Beverly Greene, Ph.D., A.B.P.P., Chair

Service Delivery and Access to Services
Joanne Hall, R.N., Ph.D., F.A.A.N., Chair

THURSDAY, MARCH 23, 2000 (cont.)

5:30 p.m. - 7:00 p.m.	**DINNER**
7:00 p.m.	**WORK GROUPS RECONVENE**

FRIDAY, MARCH 24, 2000

9:00 a.m. - 12:00 Noon	**WORK GROUP SESSIONS (cont' d.)**
12:00 Noon - 1:00 p.m.	**LUNCH**
1:00 p.m. - 3:45 p.m.	**GENERAL SESSION—***Work Groups' Report* **Suzanne Haynes, Ph.D.—Moderator (OWH)**
3:45 p.m. - 4:00 p.m.	**CLOSING**

Appendix 2: Table of IOM Recommendations Listed by Two or More Working Groups

Recommendation	Cancer	Cardiovascular	Health Promotion	HIV/AIDS	Life Span	Mental Health	Research Career	Research Methodology	Resiliency/ Homophobia	Service Delivery
Diversity studies—conduct research	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Federally funded research—solicit research on LGBT health issues	✓	✓	✓	✓	✓	✓	✓	✓	✓	✓
Scientific workshops/professional meetings—support lesbian health conferences at regular intervals	✓	✓		✓	✓	✓	✓	✓	✓	
Access and barriers to health care, information, prevention, and treatment—fund and conduct studies to explore access/barriers	✓	✓	✓	✓		✓			✓	✓
Cultural competence/sensitivity training—encourage and require sensitivity training for health care providers and researchers	✓	✓	✓			✓	✓		✓	✓

Recommendation	Cancer	Cardiovascular	Health Promotion	HIV/AIDS	Life Span	Mental Health	Research Career	Research Methodology	Resiliency/ Homophobia	Service Delivery
Sexual orientation—include sexual orientation as an analytical category in federally funded research	✓	✓	✓	✓	✓		✓	✓		
Liaison—create liaison positions, offices, and information clearinghouses for LGBT research in relevant agencies			✓		✓	✓	✓	✓		✓
Methodology—conduct research to determine appropriate methodology for studies of lesbian population	✓					✓	✓	✓	✓	✓
Discrimination/ stigma/homophobia—study impact of discrimination on mental and physical health	✓				✓	✓			✓	✓
Community—encourage researchers to collaborate with LGBT community		✓				✓			✓	✓
Datasets—fund studies using existing datasets containing sexual orientation information	✓			✓			✓	✓		

Recommendation	Cancer	Cardiovascular	Health Promotion	HIV/AIDS	Life Span	Mental Health	Research Career	Research Methodology	Resiliency/ Homophobia	Service Delivery
Sexual orientation—define, or broaden definitions to include, behavior, identity, attraction, affiliation; study identity development					✓		✓		✓	✓
Intervention—conduct studies to determine appropriate intervention strategies or to measure the effectiveness of existing programs			✓	✓					✓	✓
Mental health—fund studies of mental health stratified by other variables in the lesbian population		✓			✓	✓			✓	
Alcohol consumption—fund and conduct studies to measure alcohol use/abuse	✓	✓	✓							
Disclosure—study health effects of "outness"	✓							✓	✓	

Recommendation	Cancer	Cardiovascular	Health Promotion	HIV/AIDS	Life Span	Mental Health	Research Career	Research Methodology	Resiliency/ Homophobia	Service Delivery
Sexual minority status—include sexual minority status in programs/measures/mechanisms that apply to minority and underserved populations	✓	✓								✓
Smoking—fund studies of lesbian smoking patterns or support cessation programs tailored to LGBT women	✓	✓	✓							
Substance use/abuse—conduct studies in the lesbian population		✓		✓		✓				
Violence—study impact of anti-gay violence	✓				✓				✓	
Exercise—study rates of exercise in lesbians in relation to health	✓	✓	✓							
Healthy People 2010—include sexual orientation	✓		✓				✓			
Internet/Web—fund health-related sites for LBT women, researchers, and health care professionals			✓				✓			✓

Recommendation	Cancer	Cardiovascular	Health Promotion	HIV/AIDS	Life Span	Mental Health	Research Career	Research Methodology	Resiliency/ Homophobia	Service Delivery
NHIS—include sexual orientation	✓	✓		✓						
Aging and elderly lesbians—study patterns of aging, health risks, and health responses to aging					✓				✓	
Cancer screening—fund studies of cancer screening use, availability, and awareness in LGBT population	✓		✓							
Consortia—develop and fund lesbian health consortia						✓	✓			
Curriculum—develop lesbian health curriculum for medical schools, nursing schools, public health programs			✓						✓	
Diet—study diet compared to heterosexual counterparts and in relation to health	✓	✓								
Obesity—study prevalence of obesity in lesbians, and its relationship to health	✓	✓								

Recommendation	Cancer	Cardiovascular	Health Promotion	HIV/AIDS	Life Span	Mental Health	Research Career	Research Methodology	Resiliency/ Homophobia	Service Delivery
Over sampling techniques—encourage the use of over sampling techniques in survey research on the lesbian population	✓			✓						
YRBS—include questions about sexual orientation that examines multiple variables (ethnic, racial, socioeconomic, geographic, age, etc.) stratified by sexual orientation	✓			✓						
Family—study lesbian families, including construction of families and child rearing					✓				✓	
Insurance—study lesbian rates of health insurance coverage, domestic partner insurance, and uninsured					✓					✓
Mentor/training programs—establish mentoring and training programs for researchers studying LGBT populations						✓	✓			

Appendix 3: About the Speakers and Working Group Chairs

Judith Bradford, Ph.D.

Judith Bradford is Director of the Virginia Commonwealth University Survey and Evaluation Research Laboratory (SERL or the "Lab"). The SERL conducts applied research for local, state, and Federal government agencies, provides technical assistance to public and nonprofit community organizations, and trains graduate students in applied research methods. Dr. Bradford is a member of the core faculty for the Ph.D. Program in Public Policy and Administration (VCU Center for Public Policy), where she chairs the health policy track, and of the clinical faculty in the University's Department of Preventive Medicine and Community Health, Medical College of Virginia.

Judy is active in HIV service and applied research, having directed more than 60 HIV research projects, primarily funded by the Centers for Disease Control and Prevention or the Health Resources and Services Administration. Currently, she is Research and Evaluation Director for the Virginia HIV Community Planning Grant, funded by CDC.

Dr. Bradford has a significant interest in lesbian health research. She served on the Institute of Medicine's scientific panel studying lesbian health research priorities and recently became a member of an interdisciplinary group of Columbia University faculty who are developing a Center for Lesbian, Gay, Bisexual and Transgender Health within the Joseph L. Mailman School of Public Health. Within the Center, Judy and three lesbian research colleagues are creating an Institute for Lesbian Health Research and currently working with an emerging coalition of public and private organizations in NYC to determine and seek to address the health concerns of lesbians of color. Most recently, the Center's faculty prepared a white paper on LGBT Health for presentation at the current Healthy People 2010 conference.

Susan Y. Chu, Ph.D, M.S.P.H.

Dr. Susan Chu has been the Deputy Associate Director for Science, National Immunization Program, Centers for Disease Control and Prevention since 1997. In the late 1980' s, there was considerable controversy in the research community concerning the relationship between alcohol consumption and breast cancer. Using data from a CDC multi-site study, Dr. Chu authored a paper which received considerable scientific and media attention and helped focus national attention on the research needs in this area. She continued to build an expertise on breast cancer epidemiology and was invited by Dr. Vincent De Vita, then Director of the National Cancer Institute, to publish a book chapter for his breast cancer textbook series. Her expertise was recognized again as a member of the 1997 National Institutes of Health Consensus Panel evaluating the risks and benefits of mammography screening in women 40-49 years of age. Her most widely recognized contributions have been in HIV/AIDS research. She has authored or co-authored over 45 articles on HIV/AIDS during her six years in the HIV/AIDS Surveillance Branch, CDC, and was frequently invited to write book chapters in well-known AIDS texts. One of her early papers, entitled, "Impact of the human immunodeficiency virus epidemic on mortality among women 15-44 years of age, United States," received extensive media and political attention, and was influential in increasing awareness of the growing problem of HIV among women. This work was cited in a number of legislative reports, and was credited as playing a critical role in obtaining increased funding for HIV/AIDS research in women. By the time she was promoted to Section Chief of Special Projects, Division of HIV/AIDS, she was considered one of the primary experts at the CDC on HIV/AIDS surveillance and on the epidemiology of women and HIV. For her work in HIV/AIDS, she received the Public Health Service Commendation Medal and a Special Service Award.

Susan D. Cochran, Ph.D., M.S.

Susan D. Cochran, Ph.D., M.S., is a Professor of Epidemiology and Statistics at the University of California, Los Angeles School of Public Health where she is currently the Acting Chair of the Department of Epidemiology. Originally trained as a clinical psychologist, with a focus on behavioral medicine, her early work in experimentally improving rates of medication compliance among manic depressives is still widely cited. She is one of the early empirical researchers in the area of lesbian health, co-authoring her first paper on lesbian relationships as a graduate student in 1978. This early study of 127 lesbians demonstrated in the scientific literature that lesbians' close relationships and community identification are coherently organized along themes of emotional attachment and autonomous strivings. This may seem obvious now, but at the time, when lesbian relationships were viewed as either pathological or caricatures of heterosexual relationships, the work was considered transformational. As a graduate student, she received both the Mark Freedman Memorial Research Award and the Evelyn Hooker Research Award. She was also the recipient of a Scientist Development Award from the National Institute of Mental Health on statistical methodology in HIV research. Cochran received a M.S. in epidemiology in 1993 from UCLA's School of Public Health. She has published more than 25 articles on the health and mental health of lesbians and gay men. Her research includes studies of mental and physical health concerns among lesbians and gay men and methods of improving HIV prevention among ethnic minority gay men. Another long-standing area of research interest is women's health where she attempts to integrate an understanding of contextual factors into views of women's preventive health strategies, particularly women of color. She has published research studies on the risk of HIV infection in lesbians and women who have sex with women in a special issue of Women's Health: Research on Gender, Behavior and Policy (1996), studies on depression, alcohol use, disclosure rates to health care providers, and is currently working on a large study assessing cancer prevention in lesbians. She served as the

co-principal investigator for what still remains one of the largest studies of African American lesbians in the United States. She is currently the Principal Investigator of the Los Angeles County Lesbian Health Care Study that is examining access to care, health status, quality of services, and health-related behaviors and outcomes among lesbians. A second current focus of her work is population-based estimation of health and mental health morbidity among lesbians and gay men using data from national health surveys.

Dr. Cochran has been an American Cancer Society Postdoctoral Fellow in gynecologic oncology at UCLA's School of Medicine and was formerly teaching faculty in the Family Medicine Department of the University of Southern California. She served on the Board of the National Lesbian and Gay Health Association (NLGHA), and was the Chair of the American Psychological Association's Committee on Lesbian, Gay and Bisexual Concerns. She received the President's award from NLGHA for her leadership in gay and lesbian health and Distinguished Scientific Contributions Award from the American Psychological Association's Society for the Psychological Study of Lesbian, Gay and Bisexual Issues.

Alice J. Dan, Ph.D., M.A., B.A.

Dr. Alice J. Dan's career at University of Illinois spans more than twenty-five years. Since 1975, Dr. Dan has served as both Assistant and Associate Professor and currently Professor in the College of Nursing and School of Public Health. In 1992, she was appointed Director of the Center for Research on Women and Gender at the University, a position she still holds along with her appointment as Director of the National Center of Excellence in Women's Health in 1998.

Dr. Dan's research experience is as extensive and varied as her years at the University of Chicago. She has served as co-investi-

gator of research on such projects as Physical Activity and Bone Integrity in Middle-Aged Women, Heredity and Bone Density in Black and White Mothers and Daughters, and Self-Care Responses to Threats to Women' s Sexuality.

She has authored and co-authored over sixty articles since 1979 that have appeared in publications such as the *Psychology of Women Quarterly*, the *American Journal of Epidemiology* and the *Western Journal of Nursing Research*.

Charles H. Evans, Jr., M.D., Ph.D., F.A.A.M.A., F.A.A.S.

Charles H. Evans, Jr., M.D., Ph.D. is Senior Advisor, Biomedical and Clinical Research at the Institute of Medicine of the National Academies. He is a pediatrician and immunologist and holds the rank of Captain in the U.S. Public Health Service—retired with 27 years service as a medical scientist at the National Institutes of Health in Bethesda, Maryland, where he was Chief of the Tumor Biology Section at the National Cancer Institute from 1975-1997. Dr. Evans research interests include carcinogenesis (the etiology of cancer), the normal immune system defenses to the development of cancer, and aerospace medicine. He is an author of more than 125 scientific articles and holds three U.S. patents. Dr. Evans is the recipient of numerous scientific awards including the Outstanding Service Medal from the U.S. Public Health Service and the Wellcome Medal and Prize. He is a Fellow of the American Association for the Advancement of Science, the American Institute of Chemists, and a credentialed Fellow in Health Systems Administration of the American Academy of Medical Administrators. An active advisor to community medicine and higher education, Dr. Evans serves on the Board of Trustees of Suburban Hospital Health System and on the College of Arts & Sciences Board of Trustees at the University of Virginia.

Beverly Greene, Ph.D., A.B.P.P.

Beverly Greene, Ph.D., is a Professor of Psychology at St. John's University and a certified clinical psychologist. A Fellow of the American Psychological Association, she is a Diplomat of the American Board of Professional Psychology in Clinical Psychology. Dr. Greene serves as an editorial board member of numerous scholarly journals. In addition to these duties, she has served as founding co-editor of *Psychological Perspectives on Lesbian, Gay and Bisexual Issues (Sage)*, a series of annual publications sponsored by Division 44 of APA. She is the sole editor of the series' third volume, *Ethnic and Cultural Diversity Among Lesbians and Gay Men*, and co-editor of the recently published fifth volume: *Education, Research and Practice in Lesbian, Gay, Bisexual and Transgendered Psychology: A Resource Manual.* A recipient of numerous national awards for distinguished professional contributions and publications, she is co-editor of the forthcoming *Psychotherapy with African American Women: Innovations in Psycho Dynamic Perspectives and Clinical Applications***.**

Joanne M. Hall, Ph.D.

Joanne M. Hall, R.N., Ph.D. is an Associate Professor of Nursing at the University of Tennessee - Knoxville. Dr. Hall came to the University in 1999. From 1994-1998, she was on the faculty of the School of Nursing at the University of Wisconsin - Milwaukee. Dr. Hall's extensive research in HIV/AIDS and Lesbian Health evolved during graduate and post graduate work at the University of California - San Francisco, where she received her Ph.D. in Nursing (1992), and the University of Iowa where she received her Masters in Nursing (1982). Some of her most recent and relevant research projects include: (1) HIV Risk Reduction for Lesbians and Bisexual Women and (2) Lesbian's Alcohol Recovery Post Childhood Sexual Abuse.

Among the numerous honors she has received is the Gay and Lesbian Medical Association (GLMA) Achievement Award for Support of Human Rights and Service to the Lesbian Health Fund (1998). She also received the New Investigator Award, University of Wisconsin - Milwaukee School of Nursing (1996). She has been a Fellow in the American Academy of Nursing since 1997.

Suzanne Haynes, Ph.D.

Dr. Haynes serves as Senior Advisor for Science in the Office on Women's Health in the Department of Health and Human Services. In this position, she coordinates science initiatives for the Office. For the eight years prior to her appointment, Dr. Haynes was Chief of the Health Education Section of the National Cancer Institute, where she launched several community breast cancer screening programs, physician early detection intervention programs, and dietary change and skin cancer prevention programs. Trained as an epidemiologist, she has published 70 articles on women's health, including papers on women and heart disease, cholesterol levels, smoking, hypertension, diabetes, and breast cancer screening. She has edited the book, *How to Increase Breast Cancer Screening in Your Community*. Dr. Haynes has contributed to the work of the National Action Plan on Breast Cancer, the Canada-USA Women's Health Forum, the Federal Women's Health and the Environment Interagency Committee, and other women's health initiatives of the OWH.

Susan R. Johnson, M.D., M.S.

Dr. Susan R. Johnson received her B.S. from the University of Iowa College of Liberal Arts in 1973, her M.D. from the University of Iowa College of Medicine in 1976, and an M.S. in Preventive Medicine and Environmental Health in 1985, also from the University of Iowa. She completed residency training in Obstetrics and Gynecology at the University of Iowa Hospitals and Clinics in

1980. Dr. Johnson then joined the faculty of the University of Iowa College of Medicine in the Department of Obstetrics and Gynecology, and was promoted to Professor in 1994. Since 1994, she has served as Associate Dean for Faculty Affairs, and in 1999, was given a joint appointment in the Department of Epidemiology in the College of Public Health. She is an Examiner for the American Board of Obstetrics and Gynecology, a member of the National Board of Medical Examiners, and has served on the editorial board of the major journal in her field, *Obstetrics and Gynecology*. Dr. Johnson' s clinical and research interests are in the areas of premenstrual syndrome and menopausal health issues, particularly the use of hormones and other drugs for prevention in post-menopausal women. She directs both the PMS Clinic and the Menopause Clinic in the University of Iowa Hospital and Clinics Women' s Health Center, and serves as the Medical Director of the Family Planning Council of Iowa. She is principal investigator of the NIH sponsored Postmenopausal Estrogen/Progestin Interventions Safety Follow-up study, an investigator in the NIH-sponsored Women' s Health Initiative, and is active at the national level in the latter trial. Dr. Johnson also serves on the data, safety, and monitoring boards of three other multi-center clinical trials of various post-menopausal preventive drugs, and has written numerous articles and chapters regarding these issues.

1994-1995 National Cancer Institute Preventive Oncology Fellow; 1992-1994 National Cancer Institute Oncology Fellow; 1991-1992 American Cancer Society Fellow; 1982-1987 NIH Medical Scientist Training Program Fellow.

Mhel Kavanaugh-Lynch, M.D., M.P.H.

Dr. Kavanaugh-Lynch has served on numerous committees including the Seattle Breast and Cervical Health Program Lesbian Advisory Board and is the founder of Breast Cancer Research Funders' Network. In addition, between the years of 1994 and 1998, she has organized six conferences with emphasis on breast

cancer and one conference with the emphasis on Lesbian cancer risks entitled, *Cancer and Cancer Risks Among Lesbians*.

Raynard S. Kington, M.D., Ph.D.

Dr. Raynard S. Kington is Director of the Division of Health Examination Statistics at the National Center for Health Statistics of the Centers for Disease Control and Prevention. In this capacity he serves as Director of the National Health and Nutrition Examination Survey (NHANES), the only nationally representative study of the health of the American people based on clinical examination and biologic specimens. Dr. Kington joined NCHS In 1997 as a Research Medical Officer in the division, and prior to coming to NCHS, he was a Senior Natural Scientist in the Health Program at RAND. While at RAND, Dr. Kington was a Co-Director of the Drew/RAND Center on Health Aging, a National Institute on Aging Exploratory Minority Aging Center. Dr. Kington attended the University of Michigan, where he received his B.S. with distinction and his M.D. He subsequently completed his residency in internal medicine at Michael Reese Medical Center in Chicago. He was then appointed a Robert Wood Johnson Clinical Scholar at the University of Pennsylvania. While at the University of Pennsylvania, he completed his M.B.A. with distinction and his Ph.D. with a concentration in Health Policy and Economics at the Wharton School and was awarded a Fontaine Fellowship. He is board-certified in Internal Medicine, Geriatric Medicine, and Public Health and Preventive Medicine.

Dr. Kington's research has focused on the relationships between socioeconomic position, race, ethnicity, and health status, especially in older populations. His research has also included studies of the determinants of health care services utilization and the economic impact of health care expenditures among the elderly; determinants of the use of long-term care; the role of income and wealth in explaining racial differences in health status; and racial differences in the relationship between history of birth in the South and health status in later life.

Dee Mosbacher, M.D., Ph.D.

Dee Mosbacher, M.D., Ph.D., is a physician and film-maker. She received her Ph.D. from the Union Institute in 1979 and her M.D. from Baylor College of Medicine in 1983. She completed her psychiatric residency at Harvard University in 1987. Dr. Mosbacher then moved to San Francisco with her partner of 24 years, Nanette Gartrell, M.D., and served as Medical Director of Mental Health in San Mateo County from 1990-1995. She retired from that position to devote more time to film-making and is now a part-time psychiatric consultant as well as a film-maker .

Dr. Mosbacher is co-producer and co-director of the Academy Award nominated film *Straight from the Heart* and the multiple award-winning *All God's Children*. She is also the producer/director of "Out for a Change: Addressing Homophobia in Women' s Sports," winner of a National Educational Media Award. Dr. Mosbacher is the founder and President of Woman Vision, a non-profit educational media production company. She is a long-time activist and has served on the boards of various organizations, including Lyon-Martin Women' s Health Services (past board president), National Gay and Lesbian Task Force, American Medical Students Association, Pitzer College, and the American Association of Physicians for Human Rights (now the Gay and Lesbian Medical Association). Dr. Mosbacher has received many awards for her service to the lesbian/gay community.

Previous production credits include: "Closets are Health Hazards: Gay and Lesbian Physicians Come Out," which has been used in medical school human sexuality courses and conferences in the United States and Europe; and "Lesbian Physicians on Practice, Patients, and Power," a 30-minute video sent to every medical school in the United States and Canada by the American Association of Physicians for Human Rights. Dr. Mosbacher is currently working on a 60-minute documentary about the history of women' s music and producing a film about the life and times of Del Martin and Phyllis Lyon.

Kate O' Hanlan, M.D.

Former Associate Director of Gynecologic Cancer Surgery at Stanford University, Dr. Kate O' Hanlan' s research and publishing focus has been on cancer prevention and surgical biology of each of these cancers, as well as health issues facing lesbians and gay men. Dr. O' Hanlan founded the Lesbian Health Fund, which has made seventeen research grants totaling over $175,000. She was president of the Gay and Lesbian Medical Association and wrote "Homophobia As a Health Hazard: Report of the Gay and Lesbian Medical Association." Dr. O' Hanlan co-authored "Anti-Gay Discrimination in Medicine: Results of a National Survey of Lesbian, Gay and Bisexual Physicians." In 1994, she wrote the policy statement passed by the American Medical Women' s Association endorsing legislation for adoption and custody, and the right to marry for gay men and lesbians. Dr. O' Hanlan presented "Recruitment and Retention of Lesbians in Health Research," at the National Institutes for Health, the President' s Cancer Panel, and the Office of Research on Women' s Health asking that prevention, research, and treatment outreach efforts be focused on the gay and lesbian community. She is co-principal investigator of the NIH Grant at Stanford University, studying support and coping strategies of lesbians with breast cancer. Dr. O' Hanlan published "Lesbian Health and Homophobia: Perspectives for the Treating Obstetrician/Gynecologist," and the first Chapters on lesbian health in Copeland' s Gynecology textbook, in Behavioral Medicine.

Maureen S. O' Leary, M.I.M., R.N.

Maureen S. O' Leary is the Executive Director of the Gay and Lesbian Medical Association (GLMA), co-sponsor of the Scientific Workshop on Lesbian Health. Ms. O' Leary has been an activist in the LGBT community for the past 15 years. In addition to her work with GLMA, O' Leary has served as Vice President of the Board of Directors of the San Francisco AIDS

Foundation, Co-Chair of the Public Relations Committee of the Bay Area Non Partisan Alliance, Co-founder and chair of the Lesbians of Achievement Vision and Action awards, and founder of GLOBAL, a national organization of gay and lesbian business groups. She has worked in areas of mental health, home care, and legal services for the poor.

GLMA is an organization of almost 2,000 lesbian, gay, bisexual, and transgender physicians, medical students, and their supporters in the U.S. and 12 other countries. Founded in 1981, GLMA's mission is to promote the best possible health care for LGBT and HIV positive people, and to combat homophobia in the medical profession. GLMA administers the Lesbian Health Fund which works to strengthen the health of lesbians and their families through medical research grants and education.

Vivian W. Pinn, M.D.

Dr. Vivian W. Pinn is the first full-time Director of the Office of Research on Women's Health at the National Institutes of Health, an appointment she has held since November 1991. In February 1994, she was also named as Associate Director for Research on Women's Health, NIH. Dr. Pinn came to NIH from Howard University College of Medicine in Washington, D.C., where she had been Professor and Chair of the Department of Pathology since 1982, and has previously held appointments at Tufts University and Harvard Medical School. Dr. Pinn has long been active in efforts to improve the health and career opportunities for women and minorities. She has been invited to present the ORWH's mandate, programs, and initiatives to many national and international individuals and organizations with an interest in improving women's health and the health of minorities. She has recently led a national effort to reexamine priorities for the women's health research agenda for the 21st century, involving over 1,500 advocates, scientists, policy makers, educators and health care providers in a series of

scientific meetings across the country to determine progress as well as continuing, or emerging, areas in need of research.

Among her more recent awards and recognitions, Dr. Pinn was included among "A Dozen Who Have Risen to Prominence" in women's health, in the June 1997 New York Times Women's Health Section, and she was named the 1997 Excellence in Leadership in the Public Sector Honoree by the National Women's Economic Alliance Foundation. The American College of Physicians awarded Dr. Pinn the James D. Bruce Memorial Award in 1998 for distinguished contributions in preventive medicine; she was awarded the Athena Award in February 1999 from the Partnership for Women's Health at Columbia University; she was honored by the North American Menopause Society in September 1999; and in March 2000 she received the Catherine McFarland Award from the University of Pennsylvania for distinguished service in women's health.

Caitlin Ryan, M.S.W., A.C.S.W.

Caitlin Ryan, MSW, ACSW, is a clinical social worker who has worked on lesbian and gay health and mental health since the 1970s, and AIDS since 1982. She received her clinical training with children and adolescents in inpatient and community mental health programs, and began her social work career in school-based psycho-educational settings. A graduate of Hunter College and Smith College School for Social Work, Ms. Ryan has worked as an Instructor at Smith College School for Social Work, a faculty field Instructor at the University of Maryland School of Social Work and Community Planning, and as adjunct faculty at Catholic University School of Social Service. She is a founder and past President of the National Lesbian and Gay Health Foundation, and a founder of the National Association of People With AIDS. In 1981 she initiated and was co-investigator of the National Lesbian Health Care Survey-the first major study to identify lesbian health and mental health needs and concerns.

As a consultant to many federal and non-profit agencies, she has helped develop policies and implement services for women, adolescents, substance users and lesbians and gay men. Ms. Ryan has written numerous articles, monographs and reports for members of Congress, legislators, public officials, health and mental health providers and consumers, including the first book on AIDS policy (AIDS: A Public Health Challenge) which served as the basis for many of the recommendations of the first Presidential Commission on AIDS. Her most recent book, Lesbian & Gay Youth: Care & Counseling-the first comprehensive guide to health and mental health care for lesbian and gay youth-received an American Journal of Nursing Book of the Year Award and the Distinguished Book Award from the American Psychological Association' s Division 44. It was also published as an issue of the American Academy of Pediatrics adolescent section journal.

As a Senior Research Fellow in the Human Sexuality Studies Program at San Francisco State University, she is currently developing a study of health and mental health in self-identified lesbian, gay, bisexual, and transgender youth. Ms. Ryan has received numerous awards from professional and community-based groups, including the American Association of Physicians for Human Rights and the National Association of People With AIDS. In 1988, the National Association of Social Workers awarded her the profession' s highest honor, "National Social Worker of the Year" for her leadership and contributions to the AIDS epidemic and social change.

Randall L. Sell, Sc.D.

Dr. Randall Sell has worked in public health research since 1988 when he was hired as a Policy Analyst at the Project HOPE Center for Health Affairs. At the Center for Health Affairs he helped conduct a number of health services research studies related to HIV including several of the earliest studies examining the economic impact of the disease. He currently is the Director of the Center for Lesbian, Gay, Bisexual and Transgender Health and is

an Assistant Professor at Columbia University's Joseph L. Mailman School of Public Health. His primary area of research interest is addressing the methodological issues surrounding the sampling of sexual orientations for the conduct of public health research. Most recently, Dr. Sell coordinated the writing of a white paper on lesbian, gay, bisexual, and transgender health for the Gay and Lesbian Medical Association and Health Resources and Services Administration. Despite keeping a busy schedule at the University, Dr. Sell finds time to lend his expertise to other endeavors including serving as a consultant to the Kaiser Family Foundation; serving on the Finance Committee of the Callen-Lorde Community Health Center; and serving as Director of the Board of the New York Peer AIDS Education Coalition.

Sabrina Sojourner

Sabrina Sojourner is an African American writer, lecturer, and consultant with roots in many gardens. Her personal and professional history spans nearly 30 years and includes leadership in several progressive movements. A nationally noted feminist writer, speaker, and trainer, Ms. Sojourner has used her experience to organize grassroots campaigns in support of the passage of national and local legislation on hate crimes, a variety of health issues, lesbians and gay men in the military, civil rights, higher education, and family violence. In addition to the curriculum and training development work with the Mautner Project for Lesbians with Cancer, Ms. Sojourner works with a variety of not-for-profit and educational organizations to enhance their multicultural or government-relations activities. Her emphasis is on capacity building, including but not limited to, leadership development; staff, organizational and board development; HIV/AIDS prevention education planning and evaluation; and building multi-faith spiritual communities and rituals. She has also written, lectured, created and facilitated interactive workshops on many of those same issues. She has built an excellent reputation for her work as a mediator and facilitator. Her writings have appeared in

numerous anthologies, magazines and newspapers, and she has self-published a collection of her poems and narratives titled *Psychic Scars and Other Mad Thoughts.* Her next book, *Living By the Heart,* is due out in the summer of 2001. Ms. Sojourner also serves as the Chair of the Metropolitan Washington Regional HIV Health Services Planning Council, also known as the Ryan White Title I Planning Council. As the Chair, she guides a 60 member board through the processes necessary to meet its goals of overseeing services provided Ryan White Title I recipients.

Appendix 3. List of Acronyms

AHRQ—Agency for Healthcare Research and Quality
AIDS— Acquired immunodeficiency syndrome
APA—American Psychological Association
APHA—American Public Health Association
BMI—body mass index
BRFSS—Behavioral Risk Factors Surveillance Survey
CAPI—computer-assisted personal interview
CASI—computer-administered self-interview
CATI—computer-assisted telephone interview
CDC—Centers for Disease Control and Prevention
CSR—Center for Scientific Review
DHHS—Department of Health and Human Services
HIV— Human immunodeficiency virus
HRSA—Health Resources and Services Administration
HPV—Human papilloma virus
IC—Institute Center
IDU—injection drug user
IOM—Institute of Medicine
IRB—institutional review board
LGBT— lesbian, gay, bisexual, and transgender
MH/SA—mental health/substance abuse
NCHS—National Center for Health Statistics
NCI—National Cancer Institute
NCVS—National Crime Victim Survey
NHANES—National Health and Nutrition Examination Study
NHIS—National Health Interview Survey
NLHCS-National Lesbian health Care Survey
NIAAA—National Institute on Alcohol Abuse and Alcoholism
NIA—National Institute on Aging
NICHD—National Institute of Child Health and Human Development
NIDA—National Institute on Drug Abuse
NIH—National Institutes of Health
NIMH—National Institute of Mental Health
NSFV—National Survey of Family Violence

OPRR—Office for Protection from Research Risks
ORWH—Office of Research on Women' s Health
OWH—Office on Women' s Health
PA—program announcement
PI—principal investigator
RFA—request for application
RFP—request for proposal
RO1—type of Federal grant
SAMHSA—Substance Abuse and Mental Health Services Administration
SEER—Surveillance, Epidemiology, and End Results
STD—sexually transmitted disease
SWAN—Study of Women' s Health Across the Nation
WHI—Women's Health Initiative
YRBS—Youth Risk Behavior Survey